



THE MYOSITIS ASSOCIATION

MYONews & Updates

June 2022 | Issue Six

Upcoming Events

See our regional support group offerings plus more this [month](#)

[June 1 - NEW AFFINITY GROUP MEETING - Flying Solo \(for patients who live alone\)](#)

[June 4 - TMA Nationwide Myositis Support Group Meeting](#)

[June 16 - Ask the Doc Series](#)

[June 18 - FunFitFlex Philadelphia](#)

[June 23 - Empowerment Clinic: Living with Necrotizing Myopathy](#)

[June 26 - NEW AFFINITY GROUP MEETING - Rainbow Warriors \(for the LGBTQIA+ Community\)](#)

[June 28 - Community Convos](#)

[NEW EPISODE! TMA Myositis Family Podcast](#)

[FUN FIT FLEX](#)

[International Annual Patient](#)

THE MYOSITIS ASSOCIATION'S
**ASK THE DOC
SERIES**
Thursday JUNE 16, 2022
6:00 - 7:00 pm EST
DR. NAMITA GOYAL - NEUROLOGY

Dr. Namita Goyal is a Professor of Neurology at University of California, Irvine, and specializes in Neuromuscular Medicine. She serves as the Director of the ALS clinic, Director of the Neuromuscular Medicine Fellowship program, and co-Director of the Neuromuscular Center at UC Irvine.

Dr. Namita Goyal is a Professor of Neurology at University of California, Irvine, and specializes in Neuromuscular Medicine. She serves as the Director of the ALS clinic, Director of the Neuromuscular Medicine Fellowship program, and co-Director of the Neuromuscular Center at UC Irvine. Dr. Goyal has authored several neuromuscular articles and has given many national talks on neuromuscular diseases. In addition to evaluating and treating patients, she is a lead site investigator in several clinical trials involving neuromuscular diseases, with a special focus on ALS and myositis.

[REGISTER FOR ASK THE DOC](#)

TMA Fundraising Corner



Fundraising Event - Chuck's Art

The Myositis Association depends on the generous support of caring individuals to continue its mission. A great way to help support TMA and to build awareness is by creating your own Personal Fundraising Campaign. Sometimes, however, you may have your own special way of raising funds. Chuck Aldridge held an art show and donated a portion of the proceeds to TMA. His art was what kept him going through his worst days.

"Having been a long distance hiker and runner, dermatomyositis reduced me to relying on a wheelchair. My art was one thing that the disease could not take away. At my very worst, I could do art in a prone position."

Chuck and his wife Becky held the fundraiser at their Bed and Breakfast in Old Fort, NC and more than 60 of their friends and family attended. The fundraiser raised more than \$300 for The Myositis Association.

Do you have a creative fundraiser? Please contact TMA to explore your ideas!

A promotional banner for the Empowerment Clinic. At the top, there is a photograph of Dr. Andrew Mammen and Colleen Layton smiling. Below the photo, their names and titles are listed: "DR. ANDREW MAMMEN Neurologist" and "COLLEEN LAYTON TMA Community Member". The main title "EMPOWERMENT CLINIC" is in large, bold, white letters on a dark blue background. Below that, "LIVING WITH NECROTIZING AUTOIMMUNE MYOPATHY" is written in yellow and white. A Zoom logo is on the left. At the bottom, the date and time "Thursday June 23, 2022 6:00 - 7:00 pm EST" are displayed in white on a dark blue background.

Dr. Andrew Mammen

After obtaining his M.D. and Ph.D. at Johns Hopkins, Dr. Mammen completed his neurology residency and neuromuscular fellowship at the same institution. He co-founded the Johns Hopkins Myositis Center in 2007. He and his colleagues discovered a novel form of autoimmune myopathy associated with statin use and autoantibodies recognizing HMG-CoA reductase, the pharmacologic target of statins. In 2014, Dr. Mammen moved to the NIH, where he is an Investigator and Leader of the Muscle Disease Unit. In addition to seeing myositis patients at the NIH Clinical Center, he maintains an appointment as Adjunct Professor of Neurology and Medicine at Hopkins, where he continues to see patients at the Myositis Center.

Colleen Layton

Colleen Layton is a retired nurse who was diagnosed with Necrotizing Autoimmune Myopathy ten years ago. Colleen is a member of the TMA Patient and Family Advisory Council. She and her husband have two sons and live in New Jersey. Despite her disease, Colleen still engages in her hobby of horse-racing and is excited to share how she adapted her hobby to her illness!

REGISTER FOR EMPOWERMENT CLINIC

Community Hints & Hacks

Use doTERRA Deep Blue Rub for muscle aches. Shop around for the best price, but here is an option with 5 stars.



CLICK HERE FOR MORE
PRODUCT INFORMATION

Affinity Group Meetings



REGISTER FOR RAINBOW
WARRIORS AFFINITY GROUP

SUBMIT GENERAL QUESTIONS



FUN FIT FLEX IS BACK!

The Myositis Association
Fitness Festival • Fun Walk

Proceeds support TMA's programs for myositis patients and care partners.

 **Saturday
June 18, 2022
9:30 am
Greater Philadelphia
Montgomery County Community College**

About the event:

- Non-competitive Walk
- DJ and Music
- Children's Activities
- Fitness Demonstrations
- Health & Wellness Information
- and more...

TO REGISTER
visit www.funfitflex.org
Registration is FREE,
but participants are
encouraged to raise funds
to support the mission.

Sponsorship and vendor opportunities available. Call 800-821-7356.
www.funfitflex.org

It's TIME! Increasing Awareness, Building
Community - That's How We FLEX!



**REGISTER FOR FLYING SOLO
AFFINITY GROUP**



**REGISTER FOR MEN
MANAGING MYOSITIS
AFFINITY GROUP**



**REGISTER FOR MILITARY
VETERANS AFFINITY GROUP**

Visit www.FUNFITFLEX.org to get started with our 2022 awareness and fundraising campaign for myositis!

STEP 1:

Register to participate at either the virtual event or at one of the physical locations.

STEP 2:

Decide whether you will create a team, join an existing team, or participate as an individual.

STEP 3:

Follow the steps to create your team/personal fundraising page. Share WHY you are participating and WHY the cause is so important!

STEP 4:

Share your page link via email, on social media, and within your network of family, friends, neighbors, co-workers, and associates.

STEP 5:

Use TMA's participant resources to keep the FUN in FUNdraising!

*Participants raising a minimum of \$100 earn an official FUN FIT FLEX t-shirt!



Our 2022 Myositis Awareness Month Virtual Summit participants expressed their love of our 2022 MAM "Color Wheel" and asked that we consider creating a commemorative shirt that highlights it.

You asked, TMA has delivered!

Our Myositis Awareness t-shirt sale will be open for the next few weeks.



REGISTER FOR CAREGIVER
AFFINITY GROUP



REGISTER FOR AFFINITY
GROUP IN SPANISH -
ADELANTE!



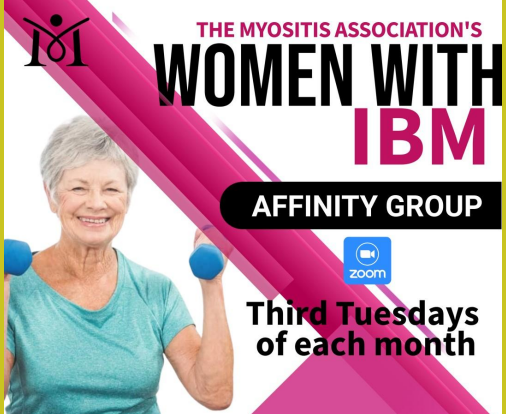
REGISTER FOR WOMEN OF
COLOR AFFINITY GROUP

Get yours!! Let the world know you are A
VOICE FOR MYOSITIS AWARENESS!

*All proceeds benefit The Myositis Association

CLICK HERE TO PURCHASE





REGISTER FOR WOMEN WITH
IBM AFFINITY GROUP

World Myositis Coalition Community Convo

WORLD MYOSITIS COALITION COMMUNITY CONVOS

Tuesday JUNE 28, 2022 6:30 PM - 8:30 PM EST



Join us for an online community "meet up"!
Meet new friends!
Talk or video chat with others in the myositis community!

CLICK HERE ON 6/28 AT 6:30 ET TO JOIN.

2022 International Annual Patient Conference



THE MYOSITIS ASSOCIATION INTERNATIONAL ANNUAL PATIENT CONFERENCE



A Focus on THE FUTURE

SEPTEMBER 8 - 11, 2022

CARIBE ROYALE RESORT
8101 WORLD CENTER DRIVE ORLANDO, FLORIDA

IN PERSON ATTENDANCE

Full Conference Experience

- Welcome and Keynote Address
- Meet The Board of Directors
- Conference Introductory Breakouts
- Getting Acquainted Sessions
- Friday and Sunday Early Bird Sessions
- Thursday – Sunday Workshop Sessions
- Medical Advisory Board Town Hall
- Q/A with Medical Advisory Board Breakouts
- Attendee Welcome Reception (Wine & Cheese)
- Bingo After Dark! Event
- Orlando FUN FIT FLEX Event
- Access to Sponsors and Exhibitors
- Prizes and Awards
- TMA Support Group Highlights
- Breakfasts and Lunches Included
- TMA Community Networking

Access to Recordings of All Sessions Post Conference

Conference Registration:

Early Bird Registration \$225/person through 5/31
Registration \$260 /person through 7/31
Registration \$295/person after 8/1

VIRTUAL PARTICIPATION

Friday and Saturday Conference Streaming of Select Workshops and General Sessions

- Three Friday Workshop Sessions Live Streamed
- Virtual Streaming of Orlando FUN FIT FLEX
- Medical Advisory Board Town Hall Live Streamed
- Q/A with Medical Advisory Board Live Streamed
- One Saturday Workshop Session Live Streamed
- TMA Community Networking via Remo Platform

Access to Recordings of All Sessions Post Conference

Conference Registration:

\$75/Household

Join Us!

www.myositis.org

REGISTER FOR APC

The Myositis Association

Before we say hello to June, let's say goodbye to Myositis Awareness Month!

We started the month with Myositis Family Day, a time to give thanks to those great souls in our support network that keep us going. We moved through the month with several webinars – Choose to Move with Brett Burton, Self-Hypnosis for Pain Management, Ask the Doc with Dr. Rohit Aggarwal, and a Clinical Study in Dermatomyositis by Alexion

Astrazenica Rare Disease.

Our Myositis Awareness Month Virtual Summit was a success with more than 200 people registered and nine sessions offered ranging from clinical trials to navigating insurance to deeper dives into myositis. For those of you who registered, remember the content is available to you for up to 30 days.

We closed out the month with a Day of Giving with a \$7,000 goal to raise much needed funds to support education, resources, advocacy, innovative research and improving the lives of people living with myositis. We are happy to report that we exceeded our goal and raised a total of \$7,576.

Yes, we have accomplished a lot together this past month, but our work isn't over. Now we turn our attention to our continued programming and especially our Fun Fit Flex events and the International Annual Patient Conference in September! TMA invites you to this 4-day in person experience featuring myositis specialists and expert presenters on everything related to myositis and its treatment. There will be educational workshops, clinical presentations, breakout sessions, networking opportunities, a multi-generational focus, patient and provider recognition, social activities, exhibitors, new conference components, and much, much more!

Until then, June is packed full of opportunities to learn, explore and have fun with your fellow community members. We invite you to get engaged!